

The Need for Lifelong Care for Adults with Congenital Heart Disease

Congenital heart disease (CHD) lasts a lifetime, even if the heart was repaired in childhood.

Adults with congenital heart disease (ACHD) have better health outcomes when they receive care at an <u>ACHD center</u>. If accessing an ACHD center is difficult, patients should talk with their cardiologist to help get this type of health care.

Working with a multidisciplinary care team

Adults with CHD may need to work with a multidisciplinary team of medical specialists to help with complex decision-making. This team may include:

- Adult congenital cardiologists care for adults with CHD and assume care when patients shift from pediatric to adult cardiology services.
- Congenital cardiac surgeons repair heart defects and abnormalities of the major blood vessels connected to the heart in people with CHD.
- **Electrophysiologists** diagnose and treat irregular heart rhythms (arrhythmias).
- Interventional cardiologists treat heart problems using catheters and minimally invasive procedures to avoid open-heart surgery.
- OB-GYNs and maternal-fetal medicine specialists help with pregnancy care and reproductive health for women.

- **Genetic counselors** help people understand how certain health conditions can be passed down to their children.
- Heart failure and transplant cardiologists treat patients with heart failure and help those who may need a heart transplant.
- **Pulmonologists** treat lung and respiratory conditions, which can impact heart health.
- **Hepatologists** diagnose and manage diseases of the liver, which may complicate heart disease.
- Other clinical care team members can include advanced practice providers, nurses and social workers.

Support during noncardiac surgeries and procedures

Adults with CHD should check with their ACHD cardiologist before any type of procedure or surgery. Their cardiologist can help identify risks and offer guidance on procedures, anesthesia and postprocedural management to help inform the best care plan.

Support for mental health

Mental health support is an important part of overall care. CHD survivors are more likely to have mental health challenges. Health care professionals should regularly check for signs of depression, anxiety and PTSD and refer patients to treatment when needed.

Heart.org/CHD



Scan to Read More

A Survivor's Story – Chris Kidwell

In 1986, at 6 days old, Chris Kidwell had surgery to switch his aorta and his pulmonary artery into the correct positions. With lifelong specialized care, he is now a father in his 30s and an avid jiu-jitsu practitioner and teacher, a passion he shares with his son Carter, who was also born with heart disease.

